Guy's and St Thomas' NHS Foundation Trust | King's College Hospital NHS Foundation Trust | Lewisham and Greenwich NHS Trust

Early Breast Cancer Stratified Follow–Up Implementation Resource Pack

December 2018

Final Version

Contents

Background and introduction

The South East London Accountable Cancer Network (SEL ACN) Living With and Beyond Cancer (LWBC) Programme has devised this network policy to standardise breast cancer follow-up care with the implementation of stratified follow up to support patients with self-management of their breast cancer aftercare.

It is a national priority to improve patient experience and outcomes for individuals living with or beyond cancer by standardising practice and reducing variation between care providers. Across SEL, there are currently differences in policies to support and follow-up individuals who have completed their breast cancer treatment. The SEL LWBC group has worked collaboratively with the SEL ACN Breast tumour group and provider trusts to drive and support the shift from clinician-led and largely hospital-based models of follow-up to an evidence based, stratified model of follow-up that addresses the unique needs of the individual patient.

In 2011, a stratified follow-up model for individuals with cancer was developed and successfully tested by NHS Improvement as part of the National Cancer Survivorship Initiative (NCSI). The model has been recommended for implementation by the NCSI in *Living with and Beyond Cancer: Taking Action to Improve Outcomes* (NCSI, March 2013).

It is a 2018-19 NHS priority that "*agreed protocols and remote monitoring systems are in place for stratifying breast cancer patients, and CCGS must demonstrate continued progress towards the 2020-21 ambition for all breast cancer patients to move to a stratified follow-up pathway after treatment."* Locally, in London, a target has been agreed that by 2020-2021, 70% of women with breast cancer will be on a supported self-management pathway. The Association of Breast Surgery (ABS) has published their 'Early Breast Cancer Person Centred Follow-up Pathway Guidelines', which also aims to standardise processes across the breast multidisciplinary team, to understand the pathway and ensure optimum follow-up care is provided to all breast cancer patients completing treatment. The protocol will also provide assurance to trusts, CCGs and any other representative that best practice 'person centred follow-up care' is being delivered.

The move toward stratified follow-up is consistent with **The Model of Care for Cancer Services** (Commissioning Support for London, 2010) which recommends a transition to personalised assessment, information provision and care planning. The rationale for this shift is that there is no evidence that traditional follow-up consisting of regular appointments in secondary care provides more effective care or better means to detect disease recurrence (CSL, 2010). In addition, longer life expectancy combined with more intensive treatments are resulting in increasing numbers of individuals living with the consequences of treatment, which may manifest long after treatment ends (Macmillan, 2013). These consequences of treatment need to be addressed by an effective model of aftercare.

In 2018, the SEL LWBC group supported the breast tumour group and provider trusts to develop and implement a stratified model of follow-up. With the permission of UCLHCC, SEL has adapted the UCLHCC LWBC Breast Stratified Follow-up Guidance and Resource Pack, which was originally published in 2014. The original guidance was reviewed and updated in November 2018 to incorporate changes in

clinical best practice, national priorities and recommendations made to Cancer Alliances by the Breast Cancer Clinical Expert Group in August 2017.[1]

Key features of stratified follow-up

The National Cancer Survivorship Initiative (NCSI) advises that individuals should be assessed to determine which tier of follow-up best meets their needs.

Key features of stratified follow-up:

- Enables people who are able to undertake self-management to do so in a safe and supported manner.
- Incorporates NCSI Recovery Package interventions (Holistic Needs Assessment, a care plan, treatment summary, and Health and Wellbeing event) to improve outcomes and care co-ordination.
- Improves patient experience by eliminating anxiety and stress induced by attending unnecessary appointments.
- Facilitates rapid re-entry into the specialist cancer service as required. This reassures individuals that they are able to access appropriate, named support quickly should they need it, without having to go via their GP. The ability to re-access services quickly and easily has been shown to be crucial to the confidence of people undertaking supported self-management, and consequently to the long term success of a supported self-management programme.
- Removal of routine follow-up appointments from the pathway. Routine surveillance mammography is still completed at set intervals. However, these do not require the individual to automatically see a hospital doctor or nurse to receive their results. The individual is sent an appointment for the tests. The results will be reviewed by an appropriately qualified staff member and the patient is informed of the results by letter, phone, or in person (as per clinical judgement).

Understanding, evaluating and learning from national pilots

In 2011 NHS Improvement supported, coached and facilitated stratified pathway development and implementation in 14 test communities in England for the National Cancer Survivorship Initiative. Lessons learned from the test sites included:

- Staff were supportive of stratification – they thought it was valuable for all patients as it allowed those that were self-managing to be empowered to move on with their lives, while those on professionally led pathways or still in treatment benefited from additional time with consultants.

- Most staff stated that patients positively received the concept of self-management if it was fully explained and introduced at an appropriate point so that it did not contrast with their expectations for follow-up care.

[1] Breast Cancer Clinical Expert Group (2017), *Clinical Advice to Cancer Alliances for the Provision of Breast Cancer Services.*

- Monitoring was extremely important for patients as a key safety measure. For those patients on a supported self-management pathway, their greatest concerns were related to their cancer returning, and recognising the signs and symptoms of cancer recurrence.
- Patients reported that the knowledge that an appropriately trained health professional reviewed their scan or blood test results was often the reassurance they needed to enter a supported self-management pathway.
- Cultural change needed to occur - many staff acknowledged that the new stratified pathways required a very different way of working and thinking for all concerned. Self-management requires a shift from a culture of dependency and reliance on professionals towards self-reliance and responsibility.

There were a number of factors that stood out as being particularly important for care coordination within a supported self-management follow-up pathway:

- Remote monitoring reassured patients that problems would get picked up and managed appropriately. This was viewed as a welcome safety net.
- Assessment and care planning was seen as crucial to effective care coordination by staff and charity contacts. Patients were less vocal about this, simply because not all of them had gone through this process at the time of the interviews. However, where it had happened, patients were positive about the care plan – they thought it was useful.
- Hand held records didn't seem to feature strongly for the patients interviewed; however, where they did have them, they could see the benefit for care coordination and their own peace of mind.
- The central role of the CNS for many patients suggests that even where patients are self-managing, the responsibility for managing whatever care may be needed has not entirely shifted to the patient.
- An IT solution to track patients put on to stratified follow-up.

There are a number of things that may need consideration for a full shift towards self-management, including:

- The broader cultural changes around how healthcare is provided, part of which is *a shift from a traditional medical model, focusing on ill health, towards a model focusing on health and wellbeing*. This brings with it broader challenges around how these cultural changes are implemented and operationalised, and how they filter through to staff and individuals with cancer.
- This then has implications for *how staff and individuals with cancer see their own role in how care is provided and received*. It requires consideration of how attitudes and awareness may be shifted in moving from a system where treatment and care is done *to* patients to a system where care is delivered in partnership with the individual.
- The challenges around this cultural shift towards self-management were particularly pertinent during the transition from treatment to aftercare, requiring patients to adjust from "being taken care of" to taking on responsibilities for their care themselves. Therefore, it is essential that

patients' expectations be managed early on in the assessment and care planning process to increase their confidence in self-managing once they have completed active treatment.

- Clear communication around new approaches to care and what this means for all involved is important. As part of this, being *more explicit about the respective roles and responsibilities* ensures that each party is aware of what is expected of them. However, making patients' responsibilities clear to them needs to go hand in hand with building their confidence to handle their own condition.
- Similarly, further training with staff to build their own confidence in this changing role may prove beneficial.
- *Longer-term implementation of the programme assists the transition* – so key principles that will enable self-management (including needs assessment, care plans, education and learning etc.) are embedded further.
- Finally, staff identified a need for *a different approach to resourcing* – nurses in particular suggested that resources may need to be moved around the system; to help with 'End of Treatment clinics,' track the patients on stratified follow–up, and administrative support.

The Early Breast Cancer Stratified Follow-up Pathway Protocol

1. Introduction and purpose of this Protocol

This document describes the redesigned stratified follow up pathway for early breast cancer[2] patients. It defines the two levels of follow-up support available to this cohort of patients which are:

1) face-to-face clinical follow-up
2) supported self-management (stratified follow-up)

and outlines which individuals are eligible for entry onto the supported self-management pathway (SSMP) for their aftercare. The document provides guidelines to ensure that:

- All individuals diagnosed with early breast cancer receive personalised information and appropriate support to enable them to live actively and well following the end of their active cancer treatment.
- A safe, robust, transparent system is utilised to manage their breast cancer surveillance program and ongoing care.
- Timely, safe and appropriate systems back into specialist services are in place in the event that a concern arises.
- Each individual is provided with verbal and written guidelines about exactly when and who to contact if they have any concerns in the future.

2. Stratified Follow-up: the process

2.1 Diagnosis and treatment

- All patients will have an HNA at diagnosis and HNA with care plan at the end of treatment. At end of treatment, a patient will also receive their treatment summary and be offered the chance to participate in a Health & Wellbeing event.

- For patients diagnosed with early breast cancer, the default position is for the patient to enter stratified follow-up, unless it is decided at clinical review that the patient is unsuitable for the self-management follow-up pathway.

[2] For the purposes of stratified follow-up in SEL, early breast cancer has been defined according to the American Joint Committee on Cancer (AJCC, 2018) for staging of breast cancer to include all primary breast cancers (stages I-III) excluding T4 and N2, M1.

- All newly diagnosed early breast cancer patients will receive information about their diagnosis, treatment and supported self-management follow-up options available to support them at the end of treatment. This will include a description of both forms of follow-up with emphasis placed on the fact that they may move between pathways if their needs change during the five year follow-up period.

- At the conclusion of the clinical review OPA, the patient is transferred onto the supported self-management (stratified follow up pathway) and will be seen in the End of Treatment clinic.

2.2 End of Treatment (EoT) clinic

- At the end of treatment, all individuals will receive an **'End of Treatment (EoT) Clinic' appointment for a clinical review**. This is an appointment between the patient and the consultant/breast care nurse where the patient will receive personalised information about their follow-up pathway and how the follow-up pathway is used to best meets their needs. The decision regarding which pathway they will enter will be formalised and included in the treatment summary generated by the doctor or breast care nurse and sent to the patient. Copies of the treatment summary will also be sent to the GP and held within the individual's hospital record.

  It is recommended that the patient be provided with verbal and/or written information regarding the following:

  - Possible treatment toxicities/consequences of treatment
  - A personal plan for future mammographic surveillance and endocrine monitoring. This will include an explanation of the process for receiving appointments for mammographic surveillance and results
  - Arrangements for a follow-up appointment with the surgical team to discuss any further surgical options, e.g. symmetrisation surgery/further reconstructive options
  - Alert symptoms that require re-access to the specialist team
  - Contact name and phone number of the breast specialist team and trust helpline
  - Breast awareness
  - Nutrition and weight
  - Alcohol awareness
  - Health and Wellbeing events
  - Any local self-help groups and useful phone numbers (e.g. Macmillan Cancer Support, Breast Cancer Care)

- The GP is sent copies of the same information that is given to the patient to provide the GP with the required information to enable them to support the individual in the primary care setting.

2.3 Living Beyond Cancer

Individuals that enter the **supported self-management pathway (SSMP):**

- Can contact BCN as needed with any concerns

- Will not have annual outpatient appointments
- Will have annual mammograms for five years with the results sent to them via post.
    - They will return to the NHS Breast Screening Programme (NBSP) once the five years are complete and the patient is over 50 years old
    - If they are under 50 years old they will continue with annual mammography until the age of screening
- MRI surveillance will be used as per guidelines for known gene carriers
- Will receive hormone therapy and bone health monitoring as per national and local guidelines
- May have surgical review as necessary to plan any further symmetrisation surgery/reconstruction options
- At any point during the five year follow-up pathway, patients may be contacted to be offered access to any relevant clinical trials that may become available.

2.4 Health and Wellbeing events

All patients will be offered an opportunity to attend a Health and Wellbeing event. Health and Wellbeing events are patient education and support sessions which aim to provide individuals with the information, reassurance and confidence they require to enable them to lead an as normal and active life as possible after their cancer treatment. They also aim to increase awareness of the local facilities and supportive care opportunities that are available to patients and their families.

The Health and Wellbeing events may be delivered as:

- **1:1 appointment** conducted with the individual at their end of treatment clinic appointment
- **Rolling programmes** (such as the 6-weekly Breast Cancer Care Moving Forward)
- **Group events** which are scheduled at regular intervals throughout the year and which individuals may have an open invitation to attend if they choose to do so. They give opportunity for interaction between patients and carers, clinicians, clinical nurse specialists, allied health professionals, and complementary therapists. These might also include market stalls of local health promotion services or voluntary agencies

It is recommended that the core content of Health and Wellbeing events is as follows:

- Expert advice on **health promotion** - to minimise risk of recurrence and support healthy living. Specifically this will include: being physically active, nutrition, healthy weight management, alcohol awareness and smoking cessation. To include information/support to effect behavioural change.
- **Support** to ensure that individuals have the confidence and skills to manage their condition themselves as far as possible – i.e. referral to rehabilitation and psychological support services and signposting to local support groups or buddying services
- Advice on **adjusting to life after treatment** – addressing fears of cancer recurrence
- Information on **signs and symptoms of recurrence** and **potential consequences of treatment**. All events should clearly convey and reinforce the methods to activate fast-track access back into the system if there are any concerns regarding new symptoms or recurrent disease
- Information and access to **financial and benefits advice**

- **Specific issues relevant to the individual's type of cancer.** For example lymphoedema – early detection and management, body image & sexual functioning
- **Vocational rehabilitation**

2.5 Discharge from the Stratified Follow-up Pathway

At the end of five years on the stratified follow-up pathway, the individual will be reviewed in a virtual MDT in order to update any ongoing treatment regimes in light of latest evidence. Any plans from this review will be actioned and a letter will be sent to both the patient and the GP to inform them of any recommendations for ongoing treatment or that the patient has been discharged from the stratified follow-up pathway and will return to the NBSP (as outlined in section 2.2).

3. Eligibility for entry onto Stratified Follow-up

All early breast cancer patients will be considered for entry onto the breast supported self- management pathway unless the clinician determines the individual unable to self-manage due to physical, cognitive, communication or emotional reasons.

For individuals participating in clinical trials, follow-up will be determined by the clinical trial protocols. All individuals taking part in clinical trials will still access and benefit from the clinical review OPA, end of treatment clinic appointment and Health and Wellbeing Events.

All patients diagnosed with early breast cancer will be entered onto the stratified follow-up pathway, unless it is decided that the patient is unsuitable for the self-management follow-up pathway due to physical, cognitive, communication, or emotional reasons. Patients will have their suitability for entering the supported self-management pathway considered at their clinical review. Those who are not eligible will be told at their clinical review and recorded as not appropriate for SSMP in their medical notes and within the cancer IT system. The clinic letter from this appointment with this information will be sent to the patient and GP.

4. Surveillance investigations

All patients will have their surveillance investigations recorded on Somerset (SCR), the cancer IT database.[3] SCR will hold the information required to manage follow up investigations - ordering, checking and results recording.

[3] SEL has agreed to utilise Somerset (SCR) cancer data system to capture and track all patients on a breast stratified follow-up pathway. At present, the SCR stratified follow-up module is not ready for use and it has been agreed that in the interim, the provider trusts in SEL will use excel spreadsheets to track and monitor patients on a breast stratified follow-up pathway. When the SCR module is available for implementation, all new patients entered onto a stratified follow-up pathway will be recorded and tracked on this system. All patients who were tracked in excel in the interim will also have their records transferred onto the SCR module to have the rest of their time on a stratified follow-up pathway monitored on SCR.

4.1 Mammography surveillance requests will be recorded on SCR. All patients will have five years of mammography on the anniversary of diagnosis (unless the consultant indicates otherwise).

4.2 Mammographic surveillance for men is not routinely undertaken.

4.3 After five years of mammography surveillance, patients will then transfer back to the NSBP. Patients not yet old enough for national screening will continue to have yearly surveillance mammograms managed through SCR until they reach screening age when they will be discharged into the NBSP.

4.4 A safe system of checking mammography required each month will be developed and implemented locally. SCR will generate a monthly list of those patients requiring mammography. The mammography request will then be made and an appointment sent to the patient. Results will be sent directly to the patient and GP and will also be recorded in SCR. Any missing results will be followed up to ensure all patients receive their surveillance (local policy in place).

4.5 Other surveillance such as for bone health and breast MRI for those at high genetic risk will be recorded and managed on an individual basis.

4.6 Patients will be aware of when their mammography surveillance is due from their end of treatment summary and their care plan. Patients will be informed to contact the specialist team if they do not receive a request for mammography by the end of the month that it is due. It is recommended that each trust locally have a system in place to outline which team members will have the responsibility to resolve issues regarding missed mammographic surveillance appointments.

5. Clinical Governance

Over the five year duration of the follow-up pathway, the clinical governance responsibility for patients on stratified follow-up pathway lies with the breast MDT. For individuals who are on the supported self-management pathway, clinical governance lies with local trust agreements.

6. Re-accessing specialist services as required

All patients and their GPs will be aware of how to access the specialist team if concerns arise within the five years on a stratified follow-up pathway. Safe, robust and sustainable open access systems will be in place to facilitate this.

6.1 Patients and their GPs will have written contact numbers and guidelines about when and how to access further support. Access will be via the Breast Care Nurse during the first five years and thereafter open access.

6.2 If a patient is required to have further investigations following their yearly mammography surveillance and they are on the stratified follow-up pathway, they will be recalled for an OPA. Patients will be prepared for this possibility at their 'End of Treatment' clinic. Patients on the stratified follow-up pathway will be seen in clinic for a review within two weeks and further investigations ordered as required.

6.3 If a patient wants to pursue delayed reconstruction/further symmetrisation they can access this pathway at any time whilst on their stratified follow-up pathway.

7. Protocol monitoring

It is recommended that auditing occur three months following the implementation of this protocol at trust level and by the breast tumour group and then on an annual basis provided there are no significant adjustments required.

Bibliography

ABS Association of Breast Surgery (2018) **Association of Breast Surgeons. Early Breast Cancer Person Centred Follow-up Pathway Guidelines. West Midlands Cancer Alliance**

AJCC (2018) **Cancer Staging Manual, 8th edn.** Chicago Illinois: The American College of Surgeons (ACS)

Armes, J. *et al*. (2009) **Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey**. *J. Clin. Oncol.* **27,** 6172–6179

Breast Cancer Clinical Expert Group (2017) **Clinical Advice to Cancer Alliances for the Provision of Breast Cancer Services**

Department of Health, Macmillan Cancer Support and NHS improvement (2011) **Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision)**

Department of Health, Macmillan Cancer Support and NHS Improvement (2013) **Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision)**

Department of Health – Quality health (2012) **Quality of life of cancer survivors in England, report on a pilot survey using Patient Reported Outcome Measures PROMS**

London Cancer (2014) **Breast Pathway Specification**

Maddams, J., Utley, M., and Moller, H (2012) **Projections of cancer prevalence in the United Kingdom, 2010-2040**. Br J. Cancer 107, 1195-1202

National Cancer Survivorship Initiative (2011) **Evaluation of adult cancer aftercare services (2011) Ipsos MORI** National Cancer Survivorship Initiative (2013) **Evaluation of adult cancer aftercare services – Follow-up Survey Report (2013) Ipsos MORI**

National Institute for Excellence (2011) **Improving Outcomes in Breast Cancer, manual update**

NHS Improvement Cancer (2012) **Innovation to Implementation: stratified pathways of care for people living with or beyond cancer. A "how to guide"**

Palin, J, Ryrie, I., Smith, L., Khanna, M., Pralat, R. (2011) **Evaluation of Health and Wellbeing Clinics: Final Report**

UCLH Cancer Collaborative (2014) **Health and Wellbeing Event Implementation Event Guidance**

UCLH Cancer Collaborative: The Cancer Alliance for North and East London **(2018) Early Breast Cancer Stratified Follow-up Implementation Resource Park**

Acknowledgements

We acknowledge the UCLHHCC (now reconfigured into UCL Partners) who kindly shared their documentation for our group to review and adapt as needed.

We acknowledge the input and expertise of all the members of the LWBC group and the SEL ACN Breast Tumour Group who participated in the development process of this stratified follow-up protocol.

We also acknowledge Guy's and St Thomas' Foundation Trust who provided examples of their GP letters, patient information leaflets and treatment summaries.

Appendix I: Definitions

Cancer IT System: The local cancer database – Somerset (SCR).

End of Treatment Clinic (EoT) appointment: The final outpatient appointment with a member of the consultant team and/or the BCN after the individual's active treatment is completed. Hormone treatment will continue beyond this.

Eligibility Criteria: An agreed description of the safety and appropriateness of entry onto the supported self-management pathway for individuals with early breast cancer.

Stratified Follow-up: A model of follow-up in which the clinical team and the person living with cancer make a decision about the best form of aftercare based on the individual's clinical and personalised needs. Individuals enter either a shared care pathway or a supported self-management pathway. The stratified follow-up pathway extends 5 years from the point of diagnosis.

Supported self-management pathway (SSMP): The stratified follow-up pathway in which patients are empowered with the knowledge and skills to self-manage their care after the end of active treatment. They are given information about the symptoms to look out for and who to contact if they notice any of these alert symptoms, future scheduled tests (e.g. annual mammography), and how to contact the specialist breast team if they have any concerns. They do not receive any further OPAs unless further investigations or support is required.

OPA: Out Patient Appointment

Treatment Summary: The treatment summary is completed by a member of the medical team at the end of primary treatment. It includes information on possible treatment toxicities and /or consequences of treatment, signs and symptoms that require referral back to a specialist team, an ongoing management plan, and a summary of information given to the individual about their cancer and future progress and any required GP actions to support the patient. Copies are sent to the GP and provided to the patient when they begin their aftercare.

Appendix II: Early Breast Cancer Stratified Follow-up Pathway reference documents

- **Reference Document A**: Patient information leaflet for supported self-management example
- **Reference Document B**: Patient clinical review invite letter example
- **Reference Document C**: GP information leaflet example
- **Reference Document D**: GP and patient clinical template letter examples– includes treatment summary, DEXA scan template letter, endocrine treatment options

A: Patient information leaflet for Supported Self-management

Why have you given me this leaflet?

You have been given this leaflet to explain the Stratified Follow-up Programme which Guy's and St Thomas' has put in place for patients who have been treated for breast diseases, including cancer.

What is open access follow-up?
Open access follow-up (OAFU) is a new type of follow-up at Guy's and St Thomas'. It is where routine, clinical examination-type appointments are replaced by a system where patients can call us when they have a problem so that they don't have to come to hospital at times when they are feeling well and symptom-free.

Why have you introduced open access follow-up?
We have introduced OAFU as it has been shown to be better for patients. It means that you don't have to make unnecessary trips to the hospital at times when you are feeling perfectly well.
Patients often find traditional clinical appointments are a source of anxiety and can lead to them being tempted to put off reporting worrying signs and symptoms if a routine clinical appointment is 'not too far away.'

Also, it's been proved that new problems are unlikely to be picked up by clinical examination alone. Most are identified by patients themselves, in between routine appointments.

Are you the only hospital to have OAFU?
No (although it may be called different things in different places). More and more hospitals across the country are changing the way patients are followed up after treatment for breast cancer and have been running it successfully for many years.

What information will I be given?
In addition to this leaflet, you will have a consultation at the end of your treatment and will be taught how to be body and breast aware, including the specific symptoms that you should report without delay to your breast care nurse.

You will also be given written information on:

- Your diagnosis and medication;
- The treatment you have had and the possible side effects;
- Signs and symptoms to report;
- Being body and breast aware;
- Arrangements for annual mammograms (and bone density scans if appropriate);
- The number which gives you fast access to your breast care nurse if you need it
- The process your breast care nurse will follow if you need to be booked back into clinic at any time in the future

Will I still be able to access the breast service in the event of concerns?
Yes. You can call the breast care nurses on their dedicated helpline telephone number if you have any queries or problems, and you will be encouraged to do so. The helpline is monitored between 0900 and 1700 Monday to Friday and you will be called back by your breast care nurse by the end of the next working day. If she feels that it would be appropriate for you to come back to clinic to be seen, you will be offered a clinic appointment, or if necessary, an appropriate diagnostic test within 14 days of your telephone call.

Will I continue to have routine mammograms?
Yes. Unless it has been otherwise specified at the end of your treatment, you will continue to be called for yearly mammograms for at least five years after your treatment, or until you are the right age to join the national NHS Breast Screening Programme. If, as a result of your specific treatment, you do not need to have annual mammograms, you will be told this, as will your GP.

Are there any other regular tests that I may need to have?

Following your treatment you and your GP will be told if you need any additional regular checks, such as bone density scans (DEXA scans). These scans can tell us if you are developing bone thinning which could lead to a condition called osteoporosis.

How the OAFU works
At the end of your treatment, you will have a special end of treatment consultation with a breast care nurse. During this appointment, she will explain exactly how the OAFU helpline works, teach you the signs and symptoms that you need to watch out for and give you the direct telephone number on which you can contact her with any symptoms or concerns.

If you need to ring this number, please leave a short message including your name, hospital number and telephone number on the answer phone. This is checked regularly from Monday to Friday between 9am and 5pm and you will be phoned back by the breast care nurse by the end of the next working day.

She will talk through with you the symptoms or concerns that you have and decide with you whether you need to be brought back into clinic or have any further diagnostic tests. If she feels this is necessary then you will be offered a clinic appointment within 14 days of phoning the helpline.

Guy's and St Thomas' NHS
NHS Foundation Trust

Breast Unit

Welcome to Stratified Follow-up

Information for Patients

B: Patient clinical review invite letter

Guy's and St Thomas' NHS
NHS Foundation Trust

Date:

Dear _____,

As you are nearing the end of the main phase of your breast cancer treatment, we would like to take this opportunity to invite you to attend a new end of treatment clinic on _____ at _____ . The clinic is held in the Breast _____ on the __ Floor. The purpose of this clinic is to help you plan any ongoing care and support you and your family may need once your treatment has finished. During the consultation, you will have the opportunity to discuss

- your overall treatment
- your plan for follow-up care and mammography
- any on-going treatment – for example hormone therapy
- any on-going physical and psychological concerns relating to your breast cancer diagnosis and treatment
- programmes and services that are available to you to support your recovery and getting back to normal
- healthy eating and lifestyle
- any other information you need at this time
- who you should contact, and how, if you have any concerns

The consultation will take about 45 minutes. Enclosed is a self-assessment form. It would be helpful if you could read and complete this and bring it with you when you attend. Please feel free to bring somebody with you if you wish.

You will be seen by either myself or one of my colleagues _____ or_____, who are both _____ working in our breast unit. You may not have met us before however it is likely we will be involved in your follow-up care as you move on from this period of treatment.

Following the consultation, you will receive a plan for your on-going care which summarises the discussions that have taken place.

If you have any questions or you are unable to make this appointment, please ring me on _____.

Yours sincerely,

C: GP Information leaflet example

Why are you sending me this leaflet?
You are being sent this leaflet because your patient, after having treatment for breast cancer at our hospital, has had their follow-up clinical review appointment with one of our consultants and a breast care nurse, and has been started on a supported self-management (SSM) follow-up pathway.

What is supported self-management follow-up?
Supported self-management replaces routine, clinical examination type appointments with a system where patients can call us if they have a problem and don't have to come to hospital at times when they are feeling well.

Why are you changing to supported self-management follow-up?
We have changed our system of follow-up because it is better for patients. It enables them to be more in charge of their own follow-up and prevents unnecessary hospital visits at a time when they may feel perfectly well. Patients often report that traditional clinical examination type follow-ups are a source of anxiety and can lead to them being tempted to put off reporting symptoms of concern if a routine clinical appointment is 'not too far away'. Also, evidence shows that most recurrences are identified by patients themselves in between routine appointments.

Are you the only hospital to have a supported self-management model of follow-up?
No (although it may be called different things in different places). More and more hospitals across the country are changing the way patients are followed up after treatment for breast cancer.

What information has my patient been given?
They have had a consultation which covered the following topics:

- Their diagnosis
- The treatment they had and some of the possible side effects
- Signs and symptoms to report
- Being body and breast aware
- Arrangements for mammograms and bone density scans (if appropriate)
- Arrangements for their bisphosphonate infusions
- Where to find further help and support,
- They have also been given written information on these topics.

Will my patient still be able to access the breast service?
Yes. Patients will be able to call the dedicated *Helpline (XXXXXXXXX)* if they have any queries or problems, and they are encouraged to do so. This telephone number is monitored regularly between 0900 and 1700, Monday to Friday and the patient will be phoned back by a breast care nurse within timescale of leaving a message. If the breast care nurse feels that it would be appropriate for the patient to come back to clinic to be seen, an appointment will be offered within 14 days of the telephone call.

How does this affect me?
It is unlikely that you will need to do anything different than you would already do for your patients after they have completed treatment for breast cancer. The attached **letter and treatment summary** gives details of the medication that you will need to continue to prescribe for your patient, as well as any additional tests that you may need to arrange for them.

Will my patient continue to have routine mammograms?
Yes. Unless it has been otherwise specified on the letter we have sent you, they will need annual mammograms for at least 5 years. At the end of 5 years, they will rejoin the standard NHS Breast Screening Programme, or if they are still below 50 years, they will continue to have annual mammograms until they reach 50, when they will join the national screening programme.

What about bone density scans?
If your patient requires bone density scans (DEXAs) this will be indicated in the letter and treatment summary attached. You will need to arrange these locally at the timescales indicated

D: GP and patient letter templates – includes Treatment Summary, DEXA scan, endocrine treatment options

Treatment Summary

Guy's and St Thomas' Cancer Centre

Breast Unit

Guy's Hospital

Great Maze Pond

London SE1 9RT

<<Patient Name (inc Salutation)>>

<<Patient Address>>

<<Patient Post Code>>

'>

<<Consultant Name>>

Department of XXXXXXX

Ref:

XXX Hospital

Address Line 1

London

Post Code

Department: 020 XXXX XXXX

Fax: 020 XXXX XXXX

<<Date>>

Dear <<Patient Name (inc Salutation)>>

At your recent appointment with the Breast cancer team we discussed Self-managed Follow-Up with you.

As part of your follow-up you will have mammograms and other tests in accordance with a standardised protocol. I enclose the written information about your surveillance, your treatment and to help you know what to be aware of in the future.

You will be contacted prior to these tests to inform you of the fact that they are due to be performed and contacted with the results.

If you require a new breast prosthesis, please ring the Breast Cancer Nurse Specialists on _____and they will help to arrange this.

If at any point you need to speak to the Breast Cancer Nurse Specialists you can and they can arrange an appointment in the next available outpatient clinic if required. You can also contact your GP and any other support services as you would normally do.

If you have any questions please do not hesitate to contact your Breast Care Nurse on _____.

Yours sincerely

Ref:{Admin.Attending_MD_ID*PnP.Initials@U}/{Ident.IDA@U}

Guy's and St Thomas' Cancer Centre

Breast Unit

Guy's Hospital

Great Maze Pond

London SE1 9RT

Appointments: 020 7188 7589

0207 188 0881

Fax: 020 7188 0923

Main Switchboard: 020 7188 7188

{Patient.First_Name@M} {Patient.Last_Name@M}

{Admin.Pat_Adr1@M}

{Admin.Pat_Adr2@M}

{Admin.Pat_City@M}

{Admin.Pat_Postal@U}

Typed: {Today@d17_b}

Dear **{patient.salutation@U} {Patient.First_Name@M} {Patient.Last_Name@M}**

TREATMENT SUMMARY

You have now completed your initial treatment for cancer. This Treatment Summary provides a summary of your diagnosis, treatment and on-going management plan. It includes information on the symptoms you should be aware of, act upon and who to contact. Your GP will also receive a copy of this summary.

Surgical Consultant	
Oncology Consultant	
Diagnosis	
Date of diagnosis	
Treatment aim	You have been treated with the intention to cure you from your breast cancer. The symptoms you are experiencing at present are expected to get better over time.
Summary of completed treatment and relevant dates:	
Surgery	The type of surgery you had was Right breast Wide local excision with no lymph nodes removedDate: Second operation: Right No further surgery with No further surgery Date:

	Third operation: Right No further surgery with No further surgery Date:
Chemotherapy	Yes ☐ No ☐ The chemotherapy you had was called…
Radiotherapy	Yes ☐ No ☐ None
On-going Services or Treatment:	
Endocrine	
Herceptin	
Ongoing Clinical studies	
Significant events during treatment	Weight loss ☐ Weight gain ☐ Menopausal symptoms ☐ Deep vein thrombosis ☐ Infection ☐ Emergency Inpatient Hospital stay ☐ Fatigue ☐ Seroma ☐ Cording ☐ Other:
Medication on completion of treatment	
Follow up	Mammogram:

	Year 1	**Year 2**	**Year 3**	**Year 4**	**Year 5**	**Year 6**	**Year 7**	**Year 8**	**Year 9**	**Year 10**
Mammogram	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
	Mammograms will be arranged									
Hospital appointment	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Dexa scan	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other tests	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other tests	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Possible Consequences of Treatment	Fertility changes Menopausal symptoms Bone density changes Psychological issues Lymphodema					Rib fractures Scarring in the lungs (fibrosis) Heart problems A new cancer				
Additional information or concerns including	Smoking cessation					Not applicable				
	Diet and weight management					For referral to weight management				

<table>
<tr><td rowspan="3">lifestyle and support needs:</td><td>Physical Activity</td><td></td></tr>
<tr><td>Moving Forward Programme</td><td>For referral</td></tr>
<tr><td>Alcohol use (Safe limit 14 units per week for females, 21 units per week for males)</td><td>Number of units per week

Advice given</td></tr>
<tr><td>Prescription Charge exemption arranged</td><td colspan="2">Yes ☐ No ☐ Not Known ☐</td></tr>
<tr><td rowspan="5">Other service referrals made:</td><td>Complementary therapies ☐</td><td>Sexual dysfunction clinic ☐</td></tr>
<tr><td>Menopause clinic ☐</td><td>Social services ☐</td></tr>
<tr><td>Psychological Support ☐</td><td>Lymphodoema Service ☐</td></tr>
<tr><td>Spiritual support ☐</td><td>Benefits advisor ☐</td></tr>
<tr><td>Other</td><td></td></tr>
<tr><td colspan="3">Signs and Symptoms to look out for and seek advice on:</td></tr>
<tr><td colspan="3">In relation to the breast :

• Lumpy area on scar line
• Lumpy area in axilla / arm pit
• Visible skin patch
• Weepy ulcer on treated breast
• Dry crusty area / itchy

Other symptoms to seek advice about:

• Pain
• Dry cough which persists
• Feeling breathless
• Constantly feeling tired
• Constant feeling of nausea / sickness
• Sudden weight loss without trying to
• Loss of appetite
• Severe headaches
• Altered vision or dizziness</td></tr>
<tr><td>Contacts for general queries advice and support</td><td colspan="2">General concerns about your health: Your GP or practice nurse

Information booklets: _____</td></tr>
<tr><td>If you require access to a member of the specialist team involved in your cancer care contact</td><td colspan="2">Normal working hours: ____

Breast Care Nurses: _____</td></tr>
</table>

	Out of hours: Your GP

Yours sincerely

Electronically Approved By:

PRIVATE AND CONFIDENTIAL

cc.

Dr {Admin.Pri_MD_ID*PnP.NameFL}

{Admin.Pri_MD_ID*PnP.Adr1@M}

{Admin.Pri_MD_ID*PnP.Adr2@M

Guy's and St Thomas' NHS
NHS Foundation Trust

Guy's and St Thomas' Cancer Centre

Breast Unit

Guy's Hospital

Great Maze Pond

London SE1 9RT

Open Access Co-ordinators: 020 7188 5585 or 7587

Main Switchboard: 020 7188 7188

<<Consultant Name>>

<<Date>>

Dear <<Patient Name (inc Salutation)>>

Your recent dexascan was within normal limits and therefore there is nothing to be concerned about.

You will be contacted with the date of your next test.

If you have any questions please do not hesitate to contact your Breast Care Nurse on _____.

Yours sincerely

cc: <<Patient GP Name>>

<<Patient GP Address>>

<<Patient GP Post Code>>